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Using Popular Culture to Enable Health Service Co-Design with Young People

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Abstract

This paper reports on participatory service design with young people with type 1 diabetes – a long-term condition that can impact their emotional wellbeing and where poor self-care often leads to negative health consequences. The paper describes a project working with young people with type 1 diabetes to design innovative health services. The project consisted of eight creative workshops, in which we used popular cultural references as a means to create enjoyable activities and encourage the young people to engage with design. These cultural references can be understood as creating design language games that allowed the young people to understand and participate in the activities required at each stage of the design process. However, not all popular culture references worked equally well and this paper explores the reasons for this.

KEYWORDS: Type 1 Diabetes, young people, co-design, healthcare, language games

1. Introduction

1.1 Young people dealing with diabetes

This paper explores the question ‘*What methodologies are effective in engaging young people with diabetes in designing healthcare services?*’. Adolescence is a sensitive period in a young person’s development. The National Children’s Bureau (2012) reports that 60% of young people in the UK feel stress about schoolwork and exams, 35% about their physical appearance, and 32% about friends.

Additionally, parents are relaxing their control whilst remaining engaged with decision-making (Anderson et al. 2002).

Young people with long-term conditions such as Type 1 Diabetes Mellitus (henceforth diabetes is a lifelong condition requiring indefinite treatment, usually by regular insulin injections, that is typically diagnosed in childhood or adolescence) have to deal with schoolwork, growing up, and boyfriend or girlfriend relationships whilst also balancing their physical activity, insulin and blood glucose level. The blood glucose levels of someone with diabetes can be affected by stress, growth, emotional excitement, illness, physical activity, food consumption and environmental temperature (Glasemann and Kanstrup 2008). Even if a young person is taking all the correct diabetes management steps he or she may still feel frustrated, ashamed, afraid, or angry (ibid.). Young people rely on the support of their parents and medical workers, as self-management is challenging to maintain (Toscos, 2010). Children with diabetes may not want to talk about their condition and this attitude becomes even stronger during adolescence when acceptance by peers becomes a central focus (Anderson et al. 1999).

The paper reflects on a ten-month project working with a group of young people with diabetes (together with family members) to design innovations in healthcare services to support self-management of their condition. Using references from popular culture, design language games were created to enable young people to participate towards the production of required design outcomes.

1.2 Young people as design partners

There have been more studies done on designing with children (Guha et.al. 2004, Druin, 2002) than with adolescents; even fewer studies report working with young people with long-term conditions. These studies have involved young people to inform design via observations (Spikol and Milrad, 2008), focus groups (Katterfeldt et.al., 2012, Arteaga et.al. 2010), interviews (Edwards et.al., 2011, Walsh et.al., 2011), questionnaires (Amin, et al. 2005, Edwards et.al., 2011), surveys (Arteaga, et.al. 2010, Walsh et.al., 2011), and user testing (Amin, et al. 2005). Other studies have adopted user-centred approaches where young people engage in making as a source of creative inspiration for designers, who then develop ideas, including the use of: workshops (Edwards et.al., 2011, Iversen and Smith, 2012, Katterfeldt et.al., 2012), visual materials and technology probes (Edwards et.al., 2011), role playing (Katterfeldt et.al., 2012), a 'cool wall' (Fitton, et.al. 2012), card sorting (Katterfeldt et.al., 2012), dot voting (Fallon, et.al. 2008, Katterfeldt et.al., 2012) and Lego Serious Play (Service Innovation Corner, 2012).

A smaller number of studies have actively involved young people directly in developing new ideas for digital products or services. For example, Katterfeldt et.al., (2012) designed a learning

platform using focus groups, workshops, role playing and paper prototyping. Iversen and Smith (2012) in designing an interactive museum exhibition, employed observations, qualitative interviews, and informal conversations; at matchmaking workshops they adopted collaborative prototyping with mock-ups. Mazzone, et al. (2008) designed computer games with small groups using semi-structured design activities, such as user storyboards, creating animated scenarios, naming emotions, and drawing and labelling facial expressions.

Reflecting on their experiences, Iversen and Smith (2012) report that they experienced problems that arose when designers deconstructed young people's design ideas and prototypes to incorporate them into new design concepts: young people were frustrated and disappointed with the partnership and considered leaving the project. Developing a shared understanding of the design process is critical to maintaining trust, and they recommend that designers need to create design space for each concept. Mazzone et.al. (2008) highlight the need for researchers to adapt to different learning styles, short attention spans, low motivation, critical behaviour and unpredictable attendance. Therefore, among others, Mazzone et.al. (ibid.) recommend working in small groups, defining simple tasks and objectives, giving clear instructions, and using many short activities with immediate outcomes. However, most relevant to this paper is the work of Glasemann and colleagues (Glasemann and Kanstrup, (2011), Glasemann et al. (2010a), Glasemann et al. (2010b), Glasemann and Kanstrup, (2008), Kanstrup et al. (2010)), who also used participatory methods to design information technology (IT) services for young people with diabetes. We examine their work in more detail in the next section.

1.3 Designing with young people with diabetes

A few studies have engaged young people with diabetes in participatory research and user-centred design. Webster (2007) has developed a co-research process in a set of workshops that focus on problem solving and goal setting: this aims to help young people develop personal strategies and gain confidence in self-managing their condition, but the approach does not consider the redesign of services. Van Staa, et.al. (2009) adopted a co-research process conducting interviews at a disco party with trained young people and chronically ill adolescents, to evaluate existing services at a paediatric hospital: however, young people were not involved in the design of hospital services. Franklin et al. (2003) describe "Sweet Talk", text messaging support for intensive insulin therapy, which was developed using a user-centred (but not participatory) software development cycle of requirement gathering, prototyping, implementation, evaluation and reporting.

Glasemann and colleagues have, over a number of years applied a co-design approach to explore IT and IT services to support self-management. Various visual materials, such as a box with tools to develop participants' own mobile diabetes support, a creativity pack, and paper prototyping were used during workshops (Glasemann and Kanstrup, 2008). Glasemann et.al. (2010b)

conducted workshops at a diabetes summer camp which included interviews, observations, food quiz games, paper prototyping and creative expression to support design of a carbohydrate counting mobile game. Glasemann and Kanstrup (2008) highlight the importance of motivation, that young people have to be empowered to see themselves as innovators, but also recognise the challenge of bridging the gap between teenagers' visionary ideas and possible implementation (Glasemann et al. 2008). They suggest that paper prototyping is an appropriate way to communicate which allows learning, reflection, understanding of users and complexity of problems, and emphasizes challenges related to specific design problems (Glasemann et.al. 2010a, Glasemann et.al. 2010b); highlight the value of exploiting the camp setting which offer particular learning environments (e.g. conversations about food issues in the cafeteria); and, report difficulties establishing discussions about diabetes and related issues, which are illustrated by low participation and motivation, disruption or silence (ibid.). Glasemann and Kanstrup (2011) recommend that it is more important to design with the focus on a person's youth rather than their condition.

Our case study differs from those above by involving young people directly in participatory design of health services provided by clinics, rather than separate technologies or specifically IT based services. It also differs in that young people were involved over an extended period (meeting in the evening, approximately once every 3 weeks, during school term time) working through a complete design process from initial collaborative analysis and creative exploration, through to devising, prototyping and evaluating new service concepts. We are now working with health service managers to implement some of these new concepts into mainstream healthcare provision.

1.4 Health Service Design Research

In recent years *service design* has been recognised as a distinct field including a professional network with associated conferences and 'Touchpoint' journal (SDN, 2013), international conferences (e.g. ServDes, 2012, ISIDC, 2012) and websites offering tools for practitioners (Tassi, 2009). Academic research into service design has followed (Mager and Sung, 2011) and the application of service design to healthcare is being explored (Mager, 2009). The design project reported in this paper is one case study in wider five-year research programme into the use of service design methods in health and social care: User-centred Healthcare Design (UCHD) funded by the UK National Institute of Health Research (NIHR). This programme aims to understand current practices of design in healthcare, develop methods of design research and practice, and gather evidence for the use of these methods. The principal methodology for this work is research through practice (Archer, 1995) where generalisable insights about *how* to design are developed through designing as a form of action research (ibid.).

2. Designing a Diabetes Service

2.1 Design Process

The full design process will be described in subsequent papers, so the focus of this paper will be on the use of popular cultural references to craft and facilitate creative design spaces. In this case study eight creative workshops were run from July 2011 to May 2012, following a process of: i.) understanding and sharing experiences; ii.) exploring blue sky ideas; iii.) selecting and developing blue sky concepts; iv.) developing practical proposals; and v.) prototyping and evaluating. Each design stage involved one or two workshops depending on the gradual evolution of the design process (see Figure 1).

All stages of the design process involved a Diabetes Specialist Nurse (DSN), a project manager (with a nursing background), and three designers acted as facilitators, with occasional input from external specialists in particular workshops. The workshops were held in seminar rooms at a conference facility close to a well-known shopping centre every two or three weeks in school term times. Workshops started at 7pm and lasted from 1.5 to 2 hours, including short breaks and refreshments.

2.2 Participants

The project participants were young people with diabetes, their siblings and parents who were members of two local support groups from Barnsley and Rotherham (South Yorkshire, UK). Ten young people with diabetes (two boys, eight girls) were involved, predominantly in their mid-teens although one 8-year-old boy participated. The number of participants varied from workshop to workshop. In most activities, participants were divided into two young peoples' groups and a parents' group.

2.3 Design Workshops

This section presents a short description of the eight workshops. The first workshop aimed to introduce both support groups (which had not met previously), develop participants' familiarity with the project, and promote a sense of project ownership. At this workshop a '*Cool-Wall*' activity inspired by the popular BBC motoring entertainment show *Top Gear* was used. In the show, presenters rate vehicles by placing photos of them on a wall labelled from 'un-cool' to 'sub-zero' (see Figure 2). Participants rated future services and products – some related to diabetes and others to everyday items from a retail catalogue – presenting their ratings at the end of the session via the group's spokespersons.

The second workshop titled '*What's it like?*', focused on understanding and sharing participants' experiences with diabetes. Two main activities were adopted at this workshop: in the first '*Marketplace*' activity each participant got a 'passport' to access a list of activities (e.g. posting on

the project website) that they were asked to complete in order to collect points. In the second *Bodymapping* activity young people were asked “*What is it like to be a young person with diabetes?*”. Participants wrote their thoughts on post-it-notes and placed them on the appropriate area of the outlined body, e.g. “*finger-pricking hurts*” was stuck on where a hand was drawn (see Figure 3, left). After twenty minutes the group presented their thoughts to the other two groups (see Figure 3, right). Based on the collected data, we created two imaginary Facebook profiles that represented a newly diagnosed 13-year-old (*Aaron*) and a long time diagnosed 16-year-old (*Katie*), and visual personas of *Aaron’s* parents.

The third and fourth workshops aimed to open the design space through developing as many blue-sky ideas as possible. Due to poor attendance the first part of the third workshop was repeated in the fourth workshop. Participants were encouraged to complete unfinished scenarios around four contexts that they had previously identified as challenging: living with diabetes at home, in the clinic, at school, and in public places (e.g. shopping centres). At both workshops various creative stimuli were employed. In an activity called ‘*Future Cinema*’ we worked to encourage the participants to open their minds and adopt an ‘anything is possible’ perspective. Participants watched a clip from a 1972 episode of the BBC TV programme ‘*Tomorrow’s World*’ (BBC, 2012). This clip presented an early predecessor of the contemporary mobile phone (see Figure 4, left). The ‘*Future Cinema*’ included important parts of the cinema going experience including tickets and popcorn.

Additionally, if idea development stalled in the group work, facilitators used one of several ‘*Blue Sky Joker Cards*’ with various fictional objects and superheroes (see Figure 4, right) or pointed participants to a reminder ‘*Anything is possible*’ object placed on the table (see Figure 4, left). Later participants had to select the three most promising ideas from the nine that were generated. In this activity, participants took on the role of judges on ‘*The X-Factor*’, which is a popular British television music competition where selected judges look for singing talent from the public, using branded evaluation sheets. Following their deliberations, we announced the ‘winners’ using cards presented in gold and silver envelopes, familiar from entertainment award shows.

The fifth workshop aimed to translate the chosen blue-sky ideas into more practical forms with potential for implementation. To achieve this a ‘*Dragons’ Den*’ another popular British BBC TV show where entrepreneurs pitch their ideas to venture capitalists (‘*Dragons*’) to convince them to invest in their businesses was implemented. With the designers’ help, participants prepared presentations using various design artefacts (e.g. cardboard glasses, storyboard frames) (see Figure 5, left). After a five minutes presentation, the *Dragons* (senior professionals from healthcare, education, diabetes, and retail) (see Figure 5, right) started to work with their chosen group to develop their idea and consider what obstacles may need to be overcome to implement it in real situations.

The sixth workshop aimed to improve existing clinical services by focussing on the flow and ownership of information touchpoints between the service and young persons, their families and carers, using visualisations inspired by the popular British animated characters *Wallace and Gromit*. Wallace is an enthusiastic inventor who tries to find creative solutions to various problems with the help of his companion dog Gromit. We adopted a cartoon machine analogy to visualise flow in an ‘information factory’ and to support discussions of alternative service designs (see Figure 6).

The seventh ‘*Role Play*’ workshop intended to prototype and evaluate the new service. Sections of the newly designed service scenarios were presented to participants using role-play by the research team and the DSN. Finally, the eighth ‘*Show and Tell*’ workshop aimed to get feedback from participants on different aspects of the proposed service design prototype (e.g. printed materials, web site, text messaging).

2.4 Final design output

The first young people’s group developed an idea called ‘*Tear-Free Testing*’, where contact lenses constantly measure glucose levels in eye moisture. If the glucose level rises above or falls below an acceptable range the contact lens will start to change colour. The change will appear in the wearer’s peripheral vision as a ‘high or low’ indicator. Collected information will get stored via Bluetooth on a smart phone app, which the young person could use at an appointment with a diabetes nurse.

The second group developed the ‘*Safety-net*’ idea: a special implant is placed in the wrist and connected with a Bluetooth sensor. The sensor can send different warning messages to screens in the house (e.g. TV or computer). For example, if the person’s glucose level is high or low, the sensor will send a message on the TV screen that the person needs to test to confirm his/her BM/blood results. Based on the results for symptoms of hyper or hypo glycemia, the message “*Calm down and eat sweets!*” will display if the person is low, if the person is high the screen will recommend to inject insulin and how much. In the case that the person is unresponsive the screen will suggest to call an ambulance.

The designers reflected on all the co-designed ideas and proposed a service called ‘*Whose Diabetes is it?*’, which offers holistic approaches to manage young person’s diabetes which might be more appropriate to their lifestyle. The proposed service includes a website (www.whosediabetesisit.org.uk) with basic information about diabetes, information and contact details of local peer support groups, information from local diabetes clinical services, social networking tools to interact with other young people with diabetes, and a text messaging service to encourage occasional immediate contact with the diabetes team in the hospital, and to receive text messages

about important news on the website. In addition, resources were designed including materials for a welcome event to introduce the service to newly diagnosed young persons and their carers, and an information folder with basic material about the service.

2.5 Design methods evaluation

As part of the wider UCHD research agenda, this project was designed to evaluate and explore our methods of working. Parts of workshops were recorded using audio recorders and photos were taken. Reflective interviews were conducted with each of the designers prior to, and following each workshop. In addition, at the end of the project a sample of workshop participants (the young people, the parents and the health professionals) were interviewed by a researcher (external to the design team).

Referring to Glasemann, et.al. (2010a) levels of engagement, participation, and motivation, we understood a good level of engagement as demonstrated by repeated attendance. (We exercise some caution in this regard as young people were brought by their parents, and we do not know to what extent they were actively choosing for themselves). Further, we believe that a trustful design space was created for the young people and their families to talk about their experiences, e.g. a 16-year-old boy who commented, “Bodymapping was ok. It opened my eyes that I have to improve it [diabetes self-care], because I was more held back in the past.” Another 13 years old girl said that she initially did not really like ‘Bodymapping’, as she did not like to talk about her condition, but, when she heard experiences from other young people, she felt quite comfortable and able to contribute.

We found that creating a design space between young people and designers (Iversen and Smith, 2012) did become problematic when our expectations were too high, or when we offered participants only a ‘blank sheet of paper’. Like Mazzone (et al. 2008), we recognised the need to change how we delivered sessions, one designer reflected: *“Participants forced us to be more creative ourselves in terms of how we take these kind of germs of ideas forward and make them slightly more interesting”*. Our effort in preparing design probes resulted in some good collaboration, and communicated to the young people that the designers valued their contribution. For example, before the ‘Dragons Den’ activity one young person said, “Oh, I don’t think I want to present. I can’t possibly do it, I don’t even know what I’m doing,” another responded, “Ah, come on, we’ve got to do it, because the Dragons are here, and it’s really important now.” The designer of this team reflected,

“When our group presented last, ... I got the kids to act, the sort of scenario out, which was a bit of a gamble, because I didn’t know whether they’d bottle [be too afraid to do] it. But they really got into it, and I was amazed how confident they were.”

Another really important issue was participants' ownership of the ideas. The design team were explicit about this in their reflections on the design sessions. A designer reported that when he suggested a few ideas one participant said "Actually do you know what, I don't like any of them." The designer said, "Right well lets design something else" and they did. The participants influenced all designers' concepts at every stage of the design process, which can be seen by the following young persons comment: "It did feel good to have your input and your information put into something that has actually come together as a whole and a project that has been designed by us". However, a designer said, "I think the important thing is to make sure they're all aware that they don't have to stick with whatever we give them because this whole process is supposed to be a co-design process."

3. Discussion: Using Popular Culture

In many of the workshops we used elements of popular culture as mechanisms to engage participants in workshop activities. These were in broadly two forms - direct references to specific instances drawn from popular culture (e.g. TV programmes, Facebook) and references to more general forms that were culturally relevant to our participants (*'Marketplace'*, *'Future Cinema'*).

In the first workshop, the Top Gear *'Cool Wall'* was adopted instead of more common icebreakers. To anonymise personal data drawn from earlier sessions, and to use participants' insights in further design activities (e.g. storyboards), designers presented the personas following the style of Facebook profiles, recognising that Facebook was both familiar and 'cool' for the young people. In the *'blue-sky'* workshops we used the cinema going experience and the *'Blue Sky Joker Cards'* to encourage divergent thinking about what might be possible. To select amongst different initial design concepts, we used the X-Factor and Dragons' Den processes as mechanisms to prioritise. Finally, in moving towards the details of practical applications we used the *'Wallace and Gromit'* style machines.

3.1 Design Language Games

Reflecting on what we had done and what was successful, we realised that we had used popular culture to enable participants to act in specific ways required for particular stages of the design process and to achieve the desired outputs for subsequent development. Such references to popular culture (and culturally-relevant forms) then enabled young people to participate in design language games (Ehn, 1988, Ehn and Kyng, 1991).

Ehn (1988) develops Wittgenstein's ideas about language games, where human activity is seen as a "language game" with unwritten rules known to all participants rather than an attempt to use language to completely describe the encountered world. In exploring the use of computers in

newspaper publication, Ehn and Kyng (1991) note how workers did not question the use of a cardboard box to represent a laser printer because that would be to ignore the rules of the language game. Their design participants could play this game because it bore a ‘family resemblance’ to language games they already knew how to play such as, in this case, the activities surrounding the use of a traditional proof machine (ibid. p. 176). However Ehn and Kyng also note the challenge for designers creating mock-ups is to “create a design language game that makes sense to all the participants” (ibid. p. 177).

The *Cool Wall*, *X-Factor*, *Dragons’ Den* and *Wallace and Gromit* approaches can be understood as efforts to frame the activities of a design process as language games familiar to our young people to serve the design work. The unwritten rules of these games provided participants with models of how they should act within the activities, e.g. rating popular appeal on the ‘*Cool Wall*’, and presenting and defending their ideas in the ‘*Dragons’ Den*’. These references enabled them to easily position themselves into required situations, which would otherwise be difficult to achieve. However, we observed that this strategy varied in its effectiveness. In some cases, the cultural references served to confuse or distract rather than frame the activity. This was particularly the case with the ‘*Wallace and Gromit*’ activity – to use Ehn and Kyng’s (1991) description, the language game did not “make sense” to participants.

We subsequently realised that in order for our language games to be understandable to participants we needed to design appropriate cues (probes) that demonstrated the game, and most importantly choose cultural references where it was very clear how the game should be ‘played’. This worked well with the *Dragon’s Den* activity where we re-created the setting of four chairs, tables with bundles of ‘money’ and branding (theme music, logo) familiar from the TV programme, and invited four new ‘players’ to be our Dragons. In contrast, whilst ‘*Wallace and Gromit*’ was a strong cultural reference, the materials we provided (machines, conveyors and pipes)(see Figure 6) to create an ‘*information factory*’ did not sufficiently express how the game should be played. The reference did not embody any particular way of behaving – inventing was a broad theme, but not a framework in which to work. Consequently participants were left bemused as to the relevance and instead discussed problems about existing services, without reference to the props. Additionally strong design input in the materials’ aesthetic distanced them from participants’ experiences and ideas.

4. Conclusions

Our work suggests some general implications for conducting service design with young people with long-term health conditions. Firstly, designers should consider young people as (equal) design partners rather than subjects of the research (Iversen and Smith, 2012): maintaining the creative momentum and incorporating young people’s insights into further design activities enhances design partnerships. Secondly, it is vital that young people feel that they own their

ideas, which must be credited as important and valuable. Dragons' Den processes provided important validation and encouragement to the young people. Our central finding relates to the effectiveness of using popular cultural references to support design language games. This strategy enabled and motivated young people, parents, carers and professionals to be active partners in an extended design process that might otherwise be difficult to understand and position themselves within. However, we have discovered that we need to select our language games carefully, and thoroughly design our props, so as to provide clear cues for participants about how such games should be *played*.

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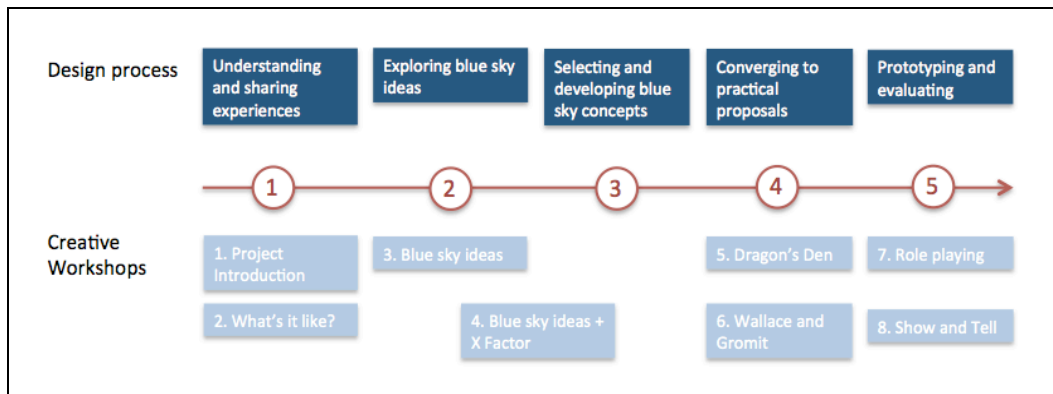


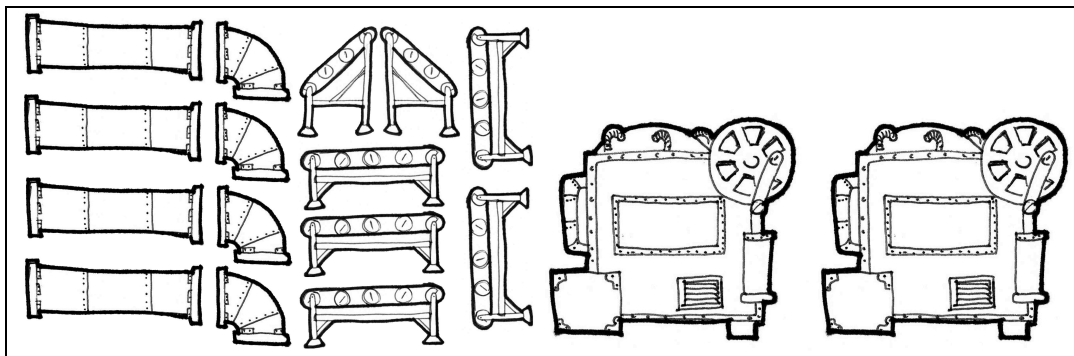
Figure 1: Adopted five-stage design process and eight creative workshops.



Figure 2: The 'Cool Wall' created by participants.



Figure 3: Bodymapping poster with post-it-notes (left) and group discussion at one of activity (right).



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